



HAEUK

Newsletter

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April 2011

HAE UK is an Association of HAE Patients, working together to improve the situation for all HAE Patients in the UK

Welcome to our HAE UK friends

It's hard to believe that six months have passed since our HAE UK Inaugural meeting last October. So much has been happening - thank you for being so patient in waiting for this news update - sorry there are no fun pictures this time!

At the end of our Inaugural meeting we set ourselves six challenges for the next decade;

- Early diagnosis
- Referral to a HAE Specialist
- Equality of access to effective HAE management
- Every patient to have possession of acute attack medication
- Every suitable patient to have access to home therapy training
- Appropriate funding for medication regardless of post code.

Well, we have been busy, busy, busy!

We have set up our HAE UK data base. It would be a great help if any HAE patients who are still having problems accessing good HAE management could let us know. It is important to know which areas of the UK are still having problems. Also, please ask all HAE patients you know to join HAE UK so that we can all support each other.

We now have a HAE UK discussion forum. Contact Rachel on: rachelannals@hotmail.com if you would like to join the forum. It is a really good way of sharing our thoughts and moving forward.

John and Ann have been meeting up with the four main pharmaceutical companies to discuss ways in which we can co-operate to help and support HAE patients.

Ann and John Price gave a presentation at the S.O.B.I. Conference in Madrid. The presentation was very well received and we made good contacts for the future. (These sunshine trips are tough, but someone has to do it!)



Dr Hilary Longhurst, Dr Mark Gompels and Sister Christine Symons have kindly agreed to be our Medical Advisory Panel.

Several HAE UK members took part in a HAE survey designed to produce a 'user friendly' questionnaire which will be valuable for use in the future.

Ann Harding and Barrie Hurley are doing great work fund raising for us - Thank you both very much.

HAE UK has become a member of Rare Diseases UK.

We were pleased to accept an invitation to join Sister Amena Warner and her patients at a Christmas party in St Helier Hospital in Carshalton. Amena ran in a London marathon to raise money for this event.

John and Ann Price attended the Rare Diseases UK Reception in the House of Commons in February. It was an opportunity to meet government ministers and to hear presentations on the needs of Rare Diseases that need to be addressed by government.

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Many HAE UK members also joined the Rare Disease UK Day in lobbying their MPs to draw attention to the fact that Rare Diseases such as HAE need to be adequately funded in the new NHS reforms.

Dr Hilary Longhurst and Ann contributed to an article on HAE for the Rare Diseases UK Supplement in the Independent Newspaper. Hilary said that with good management HAE patients could enjoy a very good quality of life, and all patients need access to appropriate treatment.

Things to come

We are hoping to have an article in the Daily Mail in the very near future.

Dr Helen Price (Ann's daughter) will join Dr Mike Tarzi for an HAE presentation at a Brighton Medical Student Symposium in May.

John Rixon will attend the HAE Conference in Budapest and he will bring back all the latest news in HAE research. He will also be meeting up with the Board of HAEI.

Individual HAE support

We have been working to give one to one support to several HAE patients over the past six months. This is one of the most important functions of a patient association. Please contact us if you want to talk about any HAE issues.

Two members in particular are facing major problems challenging PCT decisions regarding funding appropriate levels of medication to manage their HAE symptoms. Details are of course confidential, but we will report back when these members achieve funding to meet their needs.

Bristol Strategy Day, 9th April

John Rixon organised a brilliant Strategy and Planning day in Southmead Hospital. Dr Mark Gompels and Sister Christine Symons joined us as we looked at the present and future needs of HAE patients.

Dr Gompels gave a presentation about the present HAE acute attack medications, and those that will hopefully be available in the near future.

We then discussed possible strategies for achieving secure funding for HAE medications for all HAE patients in the light of the proposed new NHS Reforms.

It is so difficult to know which particular strategies would give us the best results for HAE patients.

Our website

- Ann is working away to produce the text for a 'patient friendly' HAE UK web site. Sorry this has been a long time coming.
- Our M.A.P. has kindly agreed to check the draft text and add their suggestions.
- Rachel Annals will then design an attractive and user friendly web site for us.
- Finally, we will have the site built by a professional web builder.

We hope our web site will be a really useful tool for all HAE patients to help them access effective treatment, and also to feel the support of other patients around the country.



We are talking with all interested parties to gain information and co-operation to achieve secure funding for HAE medications. Patients, Patient Associations, HAE Specialists and Pharmaceutical companies all have a common goal to see this happen. We will keep you up to date on all progress in this area.

We look forward to keeping in contact with you all and working together in HAE Patient support, as well as hearing your views on our discussion forum, or individually by contacting us.

All best wishes,
John and Kathy, and John and Ann

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